Photo courtesy of the Special Olympics Lions Club International Opening Eyes.

DISPARITIES IN CARE FOR PATIENTS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

Addressing gaps in vision and health care.

BY KATIE CONNOLLY, OD, FAAO

As the name suggests, intellectual and developmental disabilities (IDDs) encompass intellectual disabilities and developmental disabilities, such as attention-deficit/hyperactivity disorder, blindness, learning disability, etc. In the United States, approximately 17% of children have some form of developmental disability and approximately 1.2% have an intellectual disability (ID).[1-3]

Because individuals living with IDDs have greater health care needs than the neurotypical population and make up a large portion of the general population, it's essential that optometrists be equipped to care

AT A GLANCE

- Individuals living with intellectual developmental disabilities (IDDs) need additional support and care within your practice.
- Those living with IDDs have decreased access to preventative care, an increased rate of undiagnosed problems, and inappropriate use of treatments, resulting in early mortality from preventable causes.

FURTHER READING ON HEALTH EQUITY


HEALTH CARE POLICY

WHY HEALTH EQUITY MATTERS

Access to quality health care is still not a guarantee for all, but organizations are making efforts to improve population health, especially among minority groups.

BY LORI LATOWSKI GROVER, OD, PHD

Health equity is a key concept that is receiving increased attention, with a focus on how to improve population health. However, it is not uncommon for this concept to be misconstrued or poorly understood when attempting to adopt team approaches and reach agreement on priorities, whether in individual offices, large health care facilities, or in other professional groups. This article provides an overview of the current state of health equity, as well as ways you can support this mission in your own practice.

WHAT IS HEALTH EQUITY?

Health equity is an important public bridge to the diversity of health care stakeholders for building consensus, supporting dialogue, and implementing actions towards improving the overall health of people, independent of who they are or where they live. The American Public Health Association (APHA) demonstrates health inequity effectively by showing that certain groups of people are more at risk for certain diseases but have less ability to get treatment, so they are more likely to have severe health consequences or to die from treatable, preventable diseases. The APHA also explains how equity does not mean equality or simply equalizing opportunities; rather, those with worse health and fewer resources require a range of patient-specific efforts in order to achieve optimal health.

The APHA provides a wealth of resources and information on health equity on its website (www.apha.org), including an excellent educational video.[1] The Robert Wood Johnson Foundation defines health equity as a state in which "everyone has a fair and just opportunity to be as healthy as possible. This requires removing obstacles to health such as poverty, discrimination, and their consequences, including powerlessness and lack of access to jobs with fair pay, quality education and housing, safe environments, and health care."[2]

AT A GLANCE

- Health equity is achieved when everyone has the opportunity to attain their full health potential.
- Strategies to improve health equity include identifying key health disparities and understanding important determinants of health, such as health insurance, education, income status, and living and working conditions.
- Educate yourself, your team, and your patients by taking advantage of available resources on advancing health equity.

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Learn more about the importance of health equity in this recent *Modern Optometry* article by Lori Latowski Grover, OD, PhD.

for them in our practices.[4] Patients living with IDs have a 1.5 times higher rate of diabetes and die at a much younger age than the rest of the general population.[5] In a study conducted in Australia, those with IDs had a median life expectancy of 54 compared to 81 years of age in a comparison cohort.[6] Of these deaths in the population with IDs, 37% are preventable, highlighting the fact that the health care system has failed to meet the needs of these patients.[5,7,8] These are just a few of the staggering statistics that cause us to evaluate what barriers exist so we can ensure safe and quality health care for those living with IDDs (for additional reading on this topic, see *Further Reading on Health Equity*).

UNDERSTANDING IDS

An ID is a neurodevelopmental disorder that begins in childhood and causes deficits in intellectual and adaptive function. *Intellectual function* is the general ability to reason, problem-solve, plan, and use abstract thinking. Intellectual function is key to both academic learning and effective learning from experience. *Adaptive function* is a collection of conceptual, social, and practical skills that we use in our day-to-day lives. Examples include understanding and following social rules, participating in family and social activities, and completing daily living tasks, such as eating, cleaning, and other activities necessary for independent living. This means that individuals living with ID have trouble learning complex information, learning from experience, adapting to new settings, and applying knowledge. Ultimately, these issues can result in an inability to function independently.[3,7,9]

The severity of an ID varies, and the disorder is categorized as mild to moderate, profound, or severe. Mild to moderate ID (or IDD) comprises most cases. These individuals need minimal support and can often take care of themselves and learn basic life skills. Frequently, individuals are not diagnosed with ID until they are school-aged, when the learning environment starts to highlight their delay in development. Those living with profound ID are unable to live independently, need close, constant supervision, and have extremely impaired communication skills. Persons living with severe ID have a major delay in development and have impaired communication skills. They need supervision in social settings but can learn simple daily routines.[3,7,9]

HEALTH CARE GAPS

Gaps in our health care system result in improper care and can lead to many individuals living with IDD not feeling comfortable seeing a doctor.[9-11] It starts with the perception that doctors, caregivers, and health care workers have about those with IDD.[12-15] For example, in the past, there was the frequent use of shaming terminology (ie, mental retardation) in society, which lead to conscious and unconscious bias. Now, there is a concerted effort to be mindful of the words we use through many people's efforts. We also now recognize the positive contributions to society that individuals living with IDDs can make if given the appropriate resources and opportunities.

Before the 1970s, people living with IDDs were often institutionalized and segmented away from general society, further engraining both conscious and unconscious bias. In the 1970s, there was a movement to deinstitutionalize and integrate care and living in the community. Although this was positive overall, the community health care system was not ready for inclusion and still has not caught up fully.[16]

The reality in health care now is that those living with IDDs, compared to the neurotypical population, have decreased access to preventive care, inadequate health care screenings, impaired communication with providers, social barriers, lack of research for their health care needs, and lack of training for health care providers. This results in undiagnosed problems, inappropriate treatments, and ultimately, reduced quality of life and early mortality from preventable causes.[17] An unbelievable 37% of deaths that occur in the IDD population

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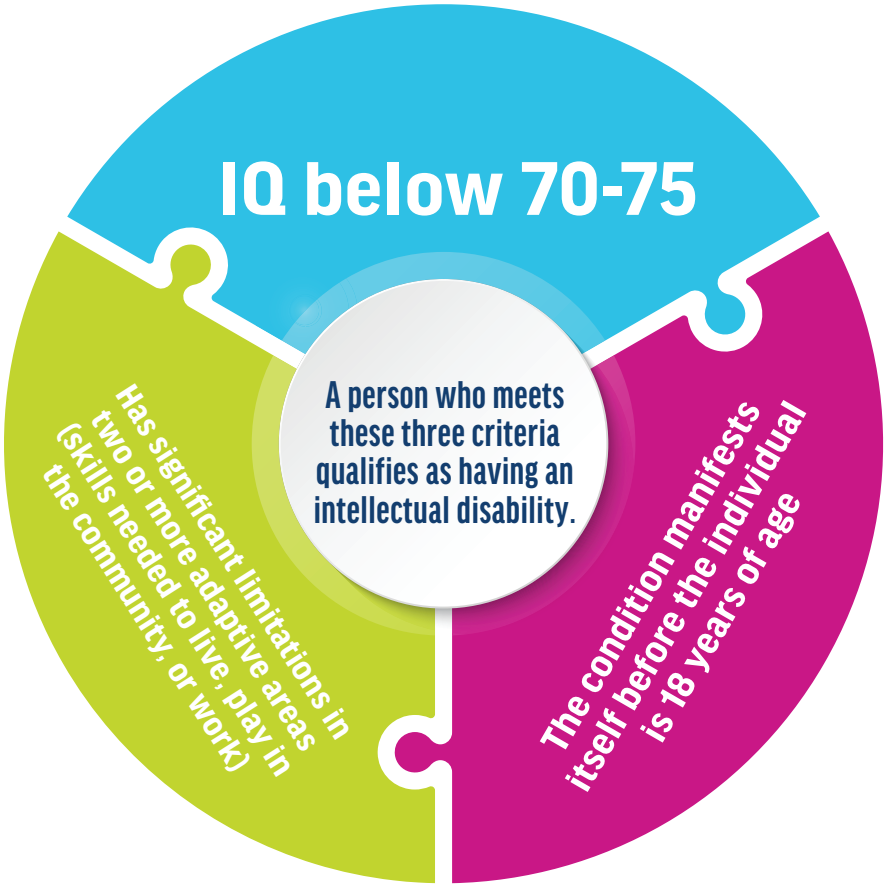
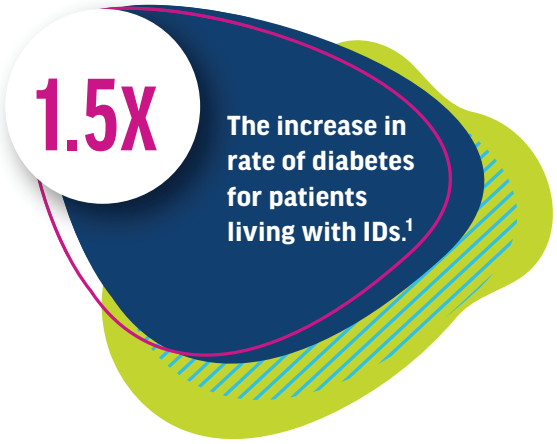
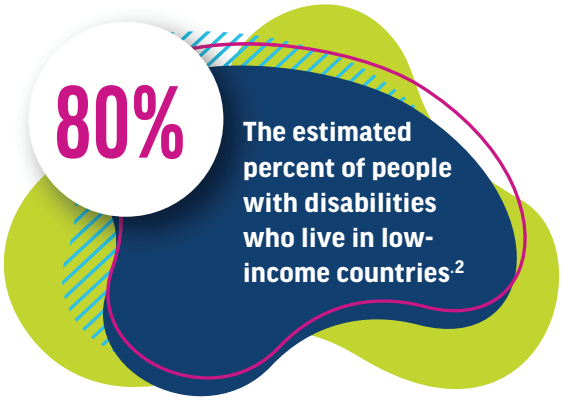
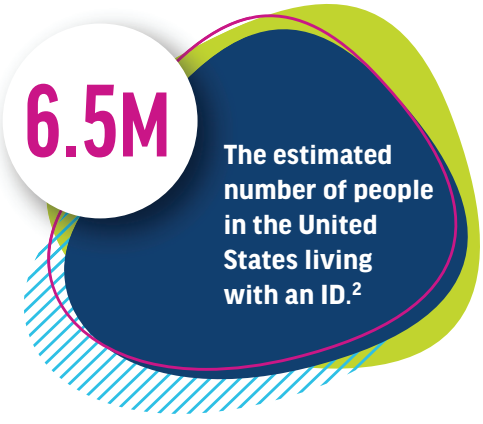
LIVING WITH ID

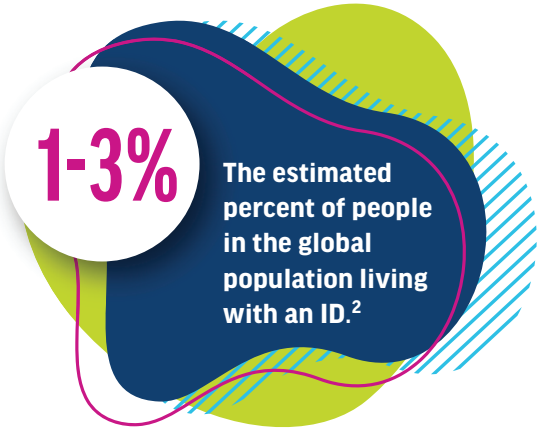






Source: Intellectual disabilities. Special Olympics. www.specialolympics.org/about/intellectual-disabilities/what-is-intellectual-disability. Accessed December 21, 2022.





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2. Intellectual disabilities. Special Olympics. www.specialolympics.org/about/intellectual-disabilities/what-is-intellectual-disability. Accessed December 21, 2022.

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could have been prevented![5,7,8] Many of these preventable deaths have been linked to health care providers failing to recognize health needs, diagnostic overshadowing, off-label use of antipsychotic medications for poor behavior, and other complex issues, such as poverty and unemployment.[7]

Solutions to these issues start with the training and attitude of health care providers, many of whom have a negative attitude toward working with those living with IDDs.[12-15] Additionally, the curriculum in medical school is not standardized across programs and countries, resulting in variability among providers.[18,19] Studies have shown that providers feel that more didactic, hands-on training is needed, but despite this, many training programs have not drastically altered their clinical training programs.[7,15,19-22] Additionally, many licensed providers have not received continuing education on caring for those living with ID since graduating, even though they work with this patient population on a day-to-day basis.[7,10,21]

A majority of medical students also feel that primary care should be provided by specialists in ID.[19,20,22] Although that may sound good in theory, the logistics of ensuring a system like this are nearly impossible. Those living with IDDs live in every community, so they need and deserve quality care close to home. This means that all community providers (eg, primary care providers, optometrists, dentists, etc) need to serve this population.

WHAT YOU CAN DO

Although many of the problems discussed here are complex and require systematic change, one simple thing you can do is break down communication barriers in your examination room. A big challenge when working with those living with IDDs can be the change in doctor-patient communication. Those living with IDDs communicate differently, or in some profound cases, hardly communicate at all, which means you need to alter how you provide care.

You can't rely as heavily on patient history or subjective responses to determine if something is wrong. You can't always rely on typical pain responses or body language to determine how much an ailment is affecting someone. What you can rely on, however, is your clinical experience and training.

If you've seen countless other patients with similar objective findings whom all presented with similar levels of discomfort, the person in front of you is likely also struggling. If their daily activities aren't currently very engaging, you don't know what their potential is if they weren't burdened by a vision disorder. Don't think only about a patient's current state; consider the simple things in their life that could be better or easier if they had improved vision.

And because communication is impaired, you should also provide eye care more frequently. One patient I saw a couple of years ago started acting differently in their care home about 2 months prior to our visit. This gentleman had experienced a retinal detachment but was unable to communicate a change in vision to his caregivers, so care was delayed. It wasn't recognized right away due to the inconsistency of caregivers at the home. Eventually, someone did recognize the change and took him to the eye doctor.

This experience motivates me to dilate all of my patients living with IDDs yearly and reminds me not to delay office visits because they may be uncomfortable for me or the patient. If anything, those with impaired communication need more frequent objective assessments that focus on prevention and improving quality of life.

I challenge you to learn more about inclusive health (#inclusivehealth) and care for all members of your community equally. ■

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